

# Precision Medicine Initiative: Building a Large U.S. Research Cohort

February 11-12, 2015

## AGENDA

### **DAY 1: Patient/Participant Centered**

8:30 am – 8:40 am	Welcome and Meeting Overview – <i>Kathy Hudson &amp; Eric Green</i>
8:40 am – 9:10 am	Vision for the Cohort and the Precision Medicine Initiative – <i>Francis Collins</i>
9:10 am – 11:10 am	<b>Reports from Workshop Planning Teams – Moderated by Rick Lifton</b> <ol style="list-style-type: none"><li>1. Building a consortium of cohorts: cohort identification and participant recruitment</li><li>2. Participant engagement, data privacy, and novel ways of returning information to participants</li><li>3. Data collection including mHealth technologies</li><li>4. Informatics and EHRs</li></ol>
11:10 am – 11:30 am	Break
11:30 am – 12:00 pm	<b>Creation of a Large U.S. Research Cohort – Moderated by Teri Manolio</b> <p>Report of NIH Cohort Inventory Findings – <i>Dave Kaufman</i></p> <p>The Million Veteran Program Cohort: An Example of a Large-Scale Health System-Based Cohort – <i>Michael Gaziano</i></p> <p>Building a Consortium of Cohorts – <i>Eric Boerwinkle</i></p>
12:00 pm – 1:15 pm	Discussion
1:15 pm – 2:15 pm	Lunch
2:15 pm – 2:45 pm	<b>Participants as Partners – Moderated by Pearl O'Rourke</b> <p>Fair Information Practices: Building Trust with Consumers– <i>Dixie Baker</i></p> <p>New Ways of Engaging Research Participants and Novel Consent Models – <i>Sharon Terry</i></p> <p>Participant Perspectives on Data Sharing: What is Important and Why – <i>Andrea Downing</i></p>
2:45 pm – 4:00 pm	Discussion
4:00 pm – 4:30 pm	Recap of Day 1 – <i>Eric Green</i>
4:30 pm	Adjourn

## DAY 2: Informatics/Data Centered

8:30 am – 8:40 am	Welcome and Goals for Day 2 – <i>Mike Lauer</i>
8:40 am – 9:10 am	<b>mHealth Technologies</b> – <i>Moderated by Bill Riley</i>  How Americans Use Technology to Track and Understand Their Health – <i>Peter Tippett</i>  Choosing Wisely: What Should be Measured in a Cohort this Large? – <i>Kevin Patrick</i>  Testing the Devices: Using the Cohort to Assess Efficacy – <i>Santosh Kumar</i>
9:10 am – 10:30 am	Discussion
10:30 am – 10:45 am	Break
10:45 am – 11:15 am	<b>Informatics Requirements and Electronic Health Records (EHRs)</b> – <i>Moderated by Daniel Masys</i>  Motivations to Participate – <i>Rex Chisholm</i>  Technical Issues in Aggregating and Analyzing Data from Heterogeneous EHR Systems– <i>Josh Denny</i>  Enhancing “Blue Button” functionality for Research – <i>Doug Fridsma</i>
11:15 am – 12:15 pm	Discussion
12:15 pm – 1:00 pm	Lunch
1:00 pm – 1:20 pm	<b>Data Access for Researchers: Guiding Principles for Data Access and Sharing</b> – <i>Moderated by Phil Bourne</i>  Data Access: Who Can Access the Data and How? – <i>Rory Collins</i>  What Protections are Needed – <i>David Ledbetter</i>
1:20 pm – 2:00 pm	Discussion
2:00 pm – 3:00 pm	<b>Discussion: Emerging Ideas from the Workshop</b> – <i>Moderated by Eric Green</i>
3:00 pm – 3:30 pm	Formulating Next Steps – <i>Rick Lifton &amp; Kathy Hudson</i>
3:30 pm – 4:00 pm	Closing Remarks – <i>Francis Collins</i>
4:00 pm	Adjourn